

Abstract 730

TITLE: Privacy and Medical Records

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The United States has made great strides in improving its understanding of people living with HIV and millions of people are committed to caring for and supporting the nearly one million people believed to be living with HIV in the United States. Nonetheless, HIV disease and AIDS remain deeply stigmatizing. The National Association of People with AIDS (NAPWA) and most consumer advocacy organizations believes that individuals must retain the right to control the disclosure of their health status. NAPWA also believes that individuals must be the primary decision-makers regarding their own health care matters and that health status cannot be permitted to be used to victimize people. For this reason, NAPWA strongly supports federal action to statutorily establish a right to privacy of an individual's health information.

The Health Insurance Portability and Accountability Act of 1996 included provisions to allow for the electronic dissemination of health information. This legislation even recognized the need for consumers to have protections against unauthorized disclosure of their medical records, by setting a time frame in which the Congress must act on this issue or the Secretary of Health and Human Services is directed to promulgate regulations to protect the privacy of an individual's health information. The Congressional deadline was August 1999. As this issue gains national attention in Washington, the Centers for Disease Control and Prevention have convened a consensus process to develop a model state public health privacy law.

This session is designed to explain the numerous considerations that call for the establishment of new federal and state protections related to personally-identifiable health information. The session will also discuss areas where broad consensus exists, and then describe several complex issues that have so far remained far more controversial, such as how easily health sciences and biomedical researchers should be able to access personal health information without getting informed consent, how to create a workable system for authorizing disclosures of information that protects a general right to privacy of a person's personal health information, and what is the relationship between differing federal and state privacy laws.

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